Informational Resource:

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Beyond Tired: Navigating the Realities of Narcolepsy & Idiopathic Hypersomnia

Not medical advice; for educational purposes only.

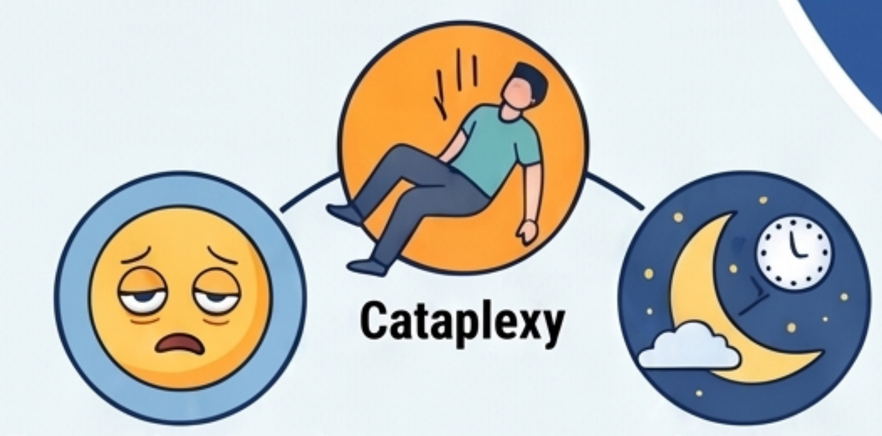
NARCOLEPSY TYPE 1 (NT1) & TYPE 2 (NT2)

NT1: Cataplexy & Loss of Orexin Neurons; **NT2:** Cataplexy Absent

A RARE NEUROLOGICAL CHALLENGE

Affects approx. 1 in 2,000 people

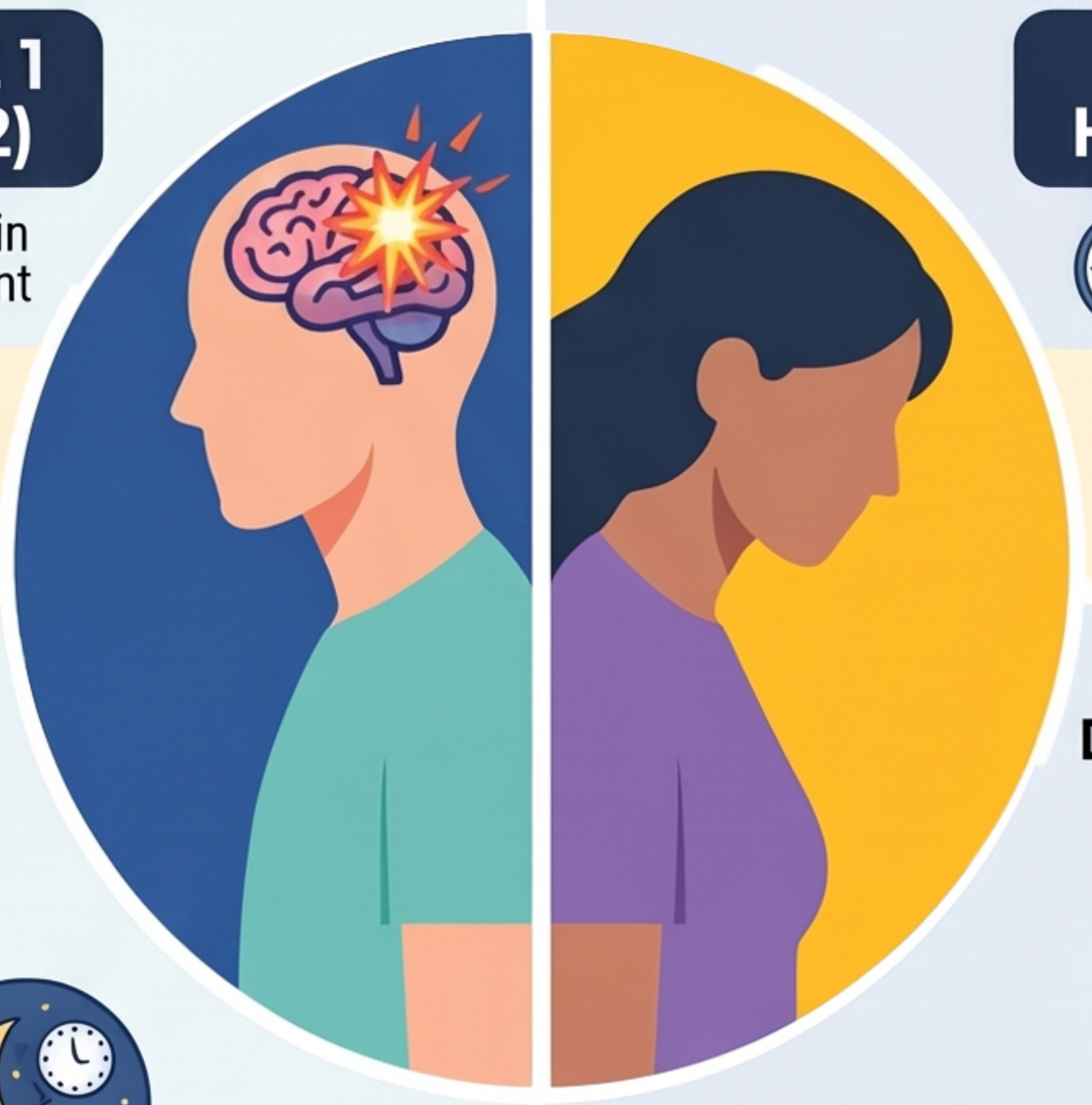
THE CLASSIC PENTAD OF NARCOLEPSY



ROOTED IN REM ABNORMALITY

Typical REM onset: **100 mins**

Narcolepsy REM onset: **<15 mins**



IDIOPATHIC HYPERSOMNIA (IH)

Extreme Need for Sleep (10-18 hours)

Diagnosed when criteria for NT1/NT2 not met; Sleep is non-restorative

IH: THE "SLEEP DRUNKENNESS" BATTLE

Sleep Inertia: Struggle to wake up, confusion, impaired balance for hours

THE HIDDEN & "INVISIBLE" BURDENS

50% SUFFER FROM PERVASIVE "BRAIN FOG": Cognitive difficulties are a top daily impact

AUTOMATIC BEHAVIOR & MICRO-SLEEPS: Up to 40% perform routine tasks without awareness/memory

HIGHER RATES OF PSYCHIATRIC DISORDERS: Social Anxiety (21.1%), Major Depression (17.1%), Panic Disorder (12.8%) compared to general population

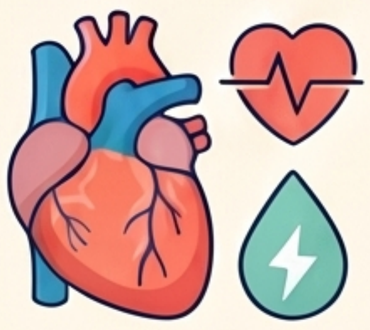
THE LIVED EXPERIENCE & IMPACT

THE 10-YEAR DIAGNOSIS GAP: Often misdiagnosed with Depression, Chronic Fatigue Syndrome, or Sleep Apnea

THE "MATH" 15-16 hrs sleep + 2-3 hrs inertia = **ONLY 5-6 HOURS OF TRUE WAKEFULNESS** for work/family

DERAILED CAREERS & RELATIONSHIPS: Limited wakefulness and being misunderstood as "lazy" or "flaky" leads to isolation and financial instability

COMPREHENSIVE CARE & COMORBIDITIES

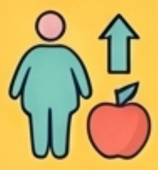


WIDESPREAD AUTONOMIC & METABOLIC DISTURBANCES: Orexin loss impacts blood pressure, heart rate, metabolic rates; higher obesity & diabetes risk

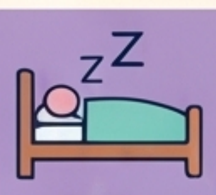
THE TREATMENT PARADOX: No single consistently effective treatment; requires individualized mix of pharmacologic & non-pharmacologic support like scheduled naps

COMORBID CONDITIONS

(Associated Risks / Findings)



METABOLIC DISORDERS: Higher obesity, diabetes, binge eating linked to orexin



SLEEP DISORDERS: 67% manage another diagnosis like Sleep Apnea or RLS

PAIN DISORDERS: Lowered pain threshold; chronic low-back pain, headaches, fibromyalgia

AUTOIMMUNE: Strong association with HLA-DQB1*06:02 allele; generalized immune vulnerability

Sources:
Maski, K. (2024). Narcolepsy: Beyond the classic pentad. Pediatric Neurology. https://pmc.ncbi.nlm.nih.gov/articles/PMC11950085/
Cook L, et al. The experience and impact of living with idiopathic hypersomnia: A qualitative study of patient perspectives shared in online media. PLOS ONE. 2024. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0333497